THE MARYLAND EARLY HEARING DETECTION AND INTERVENTION PROGRAM

Maryland EHDI and its Valued Stakeholders - Working Together

MAY 15, 2014

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Maryland Department of Health and Mental Hygiene

Prevention and Health Promotion Administration

Office for Genetics and People with Special Health Care Needs

MISSION AND VISION of the Prevention and Health Promotion Administration

MISSION

- The mission of the Prevention and Health Promotion Administration is to protect, promote and improve the health and well-being of all Marylanders and their families through provision of public health leadership and through community-based public health efforts in partnership with local health departments, providers, community based organizations, and public and private sector agencies, giving special attention to at-risk and vulnerable populations.

VISION

- The Prevention and Health Promotion Administration envisions a future in which all Marylanders and their families enjoy optimal health and well-being.

The Infant Hearing Program (IHP) is part of

The Office for Genetics and People with Special Health Care Needs (OGPSHCN)

Donna X. Harris
Director

Debbie Badawi, M.D.
Medical Director

MISSION OF OGPSHCN

The mission of the Office for Genetics and People with Special Health Care Needs (OGPSHCN) is to assure a comprehensive, coordinated system of care that meets the needs of Maryland's children and youth with special health care needs and their families and is community-based, family-centered and culturally competent.

Vision of OGPSHCN

- The vision of the Office for Genetics and People with Special Health Care Needs is to become a nationally recognized leader in developing the unique potential of each Maryland child and young person served through its comprehensive, fully integrated and consumer-friendly system of care.

Current OGPSHCN Organizational Structure

Infant and Children Follow Up Services:

- Sickle Cell Disease
- Children's Medical Services
- Infant Hearing
- Newborn Screening Follow Up
- Birth Defects and Reporting Information System
- Critical Congenital Heart Disease (CCHD) Screening

Infrastructure and Systems Development

- Systems of Care
- Medical Homes
- Youth Transition
- Grants Administration
- Family Resource Coordination

Mission of The Maryland Infant Hearing Program

To promote the best communication outcomes for infants with a permanent hearing status that affects speech-language skills by creating and maintaining systems of care that identify these infants and ensure their referral to appropriate intervention services at the earliest possible age.

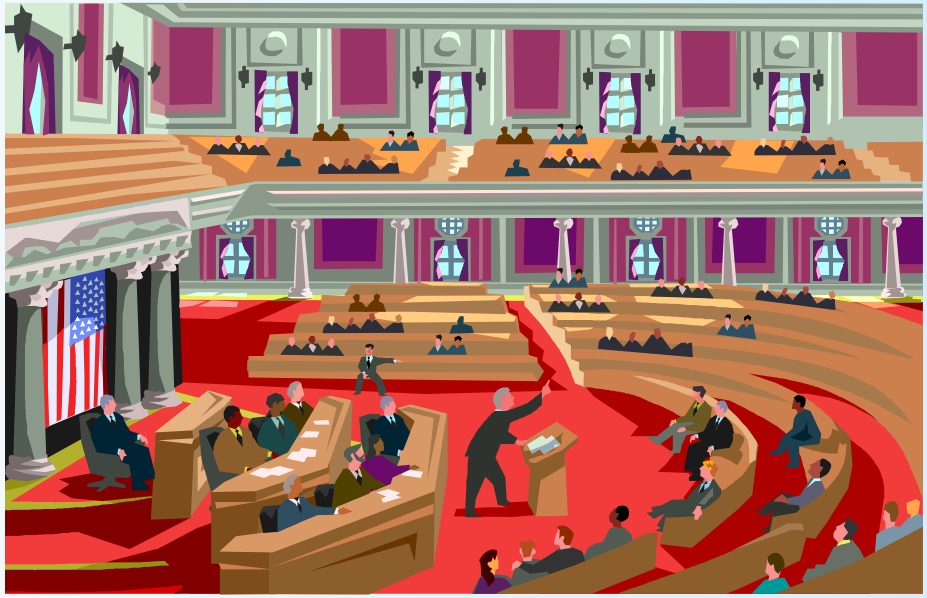
1-3-6 Principle

Goals of EHDI (Early Hearing Detection and Intervention) endorsed by the JCIH, AAA, ASHA and the AAP

- Hearing Screening by 1 month of age
- Hearing status determination/hearing loss identification by 3 months of age
- Intervention by 6 months of age

Children who have a hearing status that may affect speech and language development who do not receive intervention services by 6 months of age, are at greater risk for delays in speech and language development.

Legislation



Federal Legislation

- 1999 NY Rep. Jim Walsh introduced the “Newborn and Infant Screening and Intervention Act” to create the EHDI program within the U.S. Department of Health and Human Services
- Currently 46 states have legal mandates for universal newborn hearing screening (ASHA website)
- EHDI programs exist in all 50 states

Maryland EHDI Legislation

Original Statute: effective July 1, 2000

Maryland Health-General Article, Sec. 13-601-604, Annotated Code of Maryland, **Universal Newborn Hearing Screening**

- All newborns to undergo hearing screening before hospital discharge
- Insurance Companies required to cover cost of screening and one diagnostic evaluation
- Birth hospitals required to report results of newborn hearing screening to DHMH

SB103 to revise original Statute Signed into law April, 2014 effective July 1, 2014

Changes to Md. HEALTH-GENERAL Code Ann. §§13-601-13-605:

(1) **Maryland Early Hearing Detection and Intervention Program and the Maryland Early Hearing Detection and Intervention Advisory Council renamed**
(2) **Adds representative from the Governor's Office of the Deaf and Hard of Hearing to the advisory council**
(3) **Minimum number of advisory council meetings per year changed from 6 to 4**
(4) **Council member term limit established as 3 years**
(5) **Removes all instances of "hearing impaired, hearing impairment"; uses "permanent hearing status that affects speech-language skills"**
(6) **Allows DHMH to adopt regulations for results reporting procedures for hospitals, birthing sites, and audiologists**

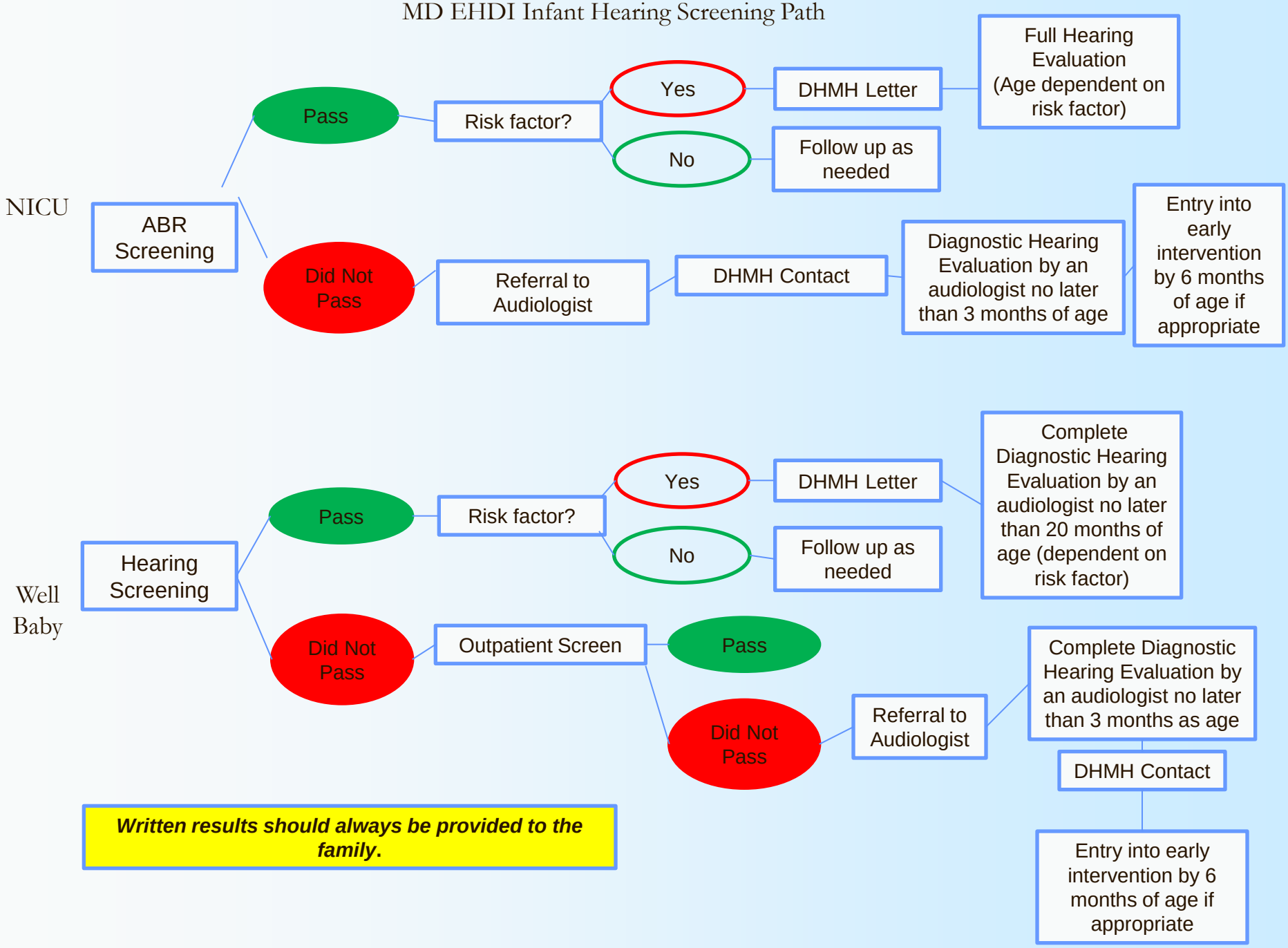

MAY 5 '14
SB 58
HB 440

Anticipated Updates to the UNBHS Regulations (COMAR 10.11.02) (currently in process – will include stakeholder input)

1. **Align language using "hearing status"**
2. **Remove references to the High Risk Questionnaire; list risk factors for later onset hearing loss per national Joint Committee on Infant Hearing (JCIH)**
3. **Require audiologists to report hearing screening and diagnostic evaluation results to the Maryland EHDI Program/DHMH**
4. **Establish reporting procedures for out of hospital births**

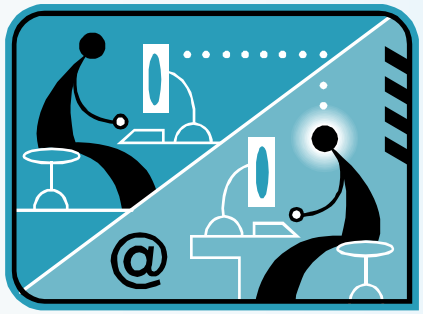
MARYLAND
Department of Health and Mental Hygiene

MD EHDI Infant Hearing Screening Path



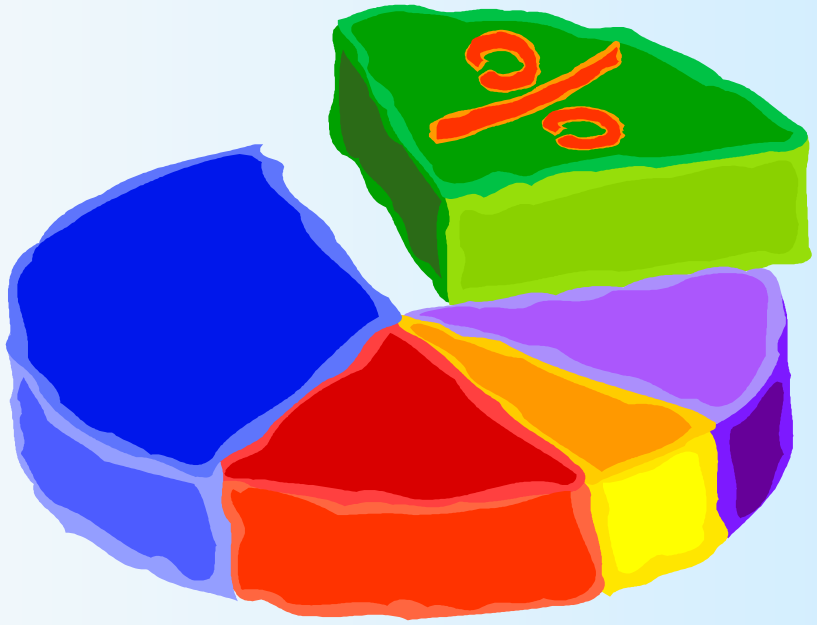
Reporting test results to MD EHDI

www.mdehdi.com



- Web-based, real-time, access anywhere, anytime, no software installations required
- User access through secure user name and password

STATISTICS



Calendar Year 2012 Statistics

- Total Maryland births
  69,891
  - 357 (inpt deceased/refused/ not indicated, etc.)
  69,534 infants who needed a screen
- Documented hearing screen while inpt
  69,498/69,534 = 99.95%
- Documented diagnostic eval
  581
- 78 screened have permanent hearing loss

Calendar Year 2012 Statistics

Over 99% inpatient screening rate

- 8 non-transient conductive HL
- 62 sensorineural hearing loss
- 4 mixed hearing loss
- 2 Auditory Neuropathy
- 17 incomplete but strong suspicion of perm HL
- 5 Late onset
- 88 infants documented as referred to the Infants and Toddlers Program

Preliminary Calendar Year *2013* Statistics (as of May, 2014)

- Total Maryland births 69,132
- Total passed inpatient screen 65,857
- Total did not pass inpatient screen 2,211
- Total missed inpatient screen 706 (408 were OOH births)
- Total not screened as inpatient 358

Out of the 358 not screened as inpatient:

259 deceased

13 transferred out of state

6 medical reasons for not conducting screen

Preliminary Calendar Year *2013* Statistics (as of May, 2014)

Total Needing follow-up	2,917
Total became ineligible for follow-up (moved, refused, became ill, deceased)	127
Rescreen of diagnostic test result was normal	2,104
Total diagnosed with hearing loss	93
Total hearing status Not Yet Determined	61
Total Lost to Follow-Up/Lost to Documentation (133 of these were born Out of Hospital)	558

Hearing Advisory Council

- **Made up of 11 board members:**
  - **1 Physician with expertise in childhood hearing status determination**
  - **1 Maryland State Department of Educ. representative**
  - **1 Maryland School for the Deaf representative**
  - **1 Educator of the deaf from a Local Education Agency**
  - **1 MD Department of Health and Mental Hygiene representative**
  - **1 mental health professional with expertise in the area of deafness**
  - **2 parents of a child who has a hearing status that affects speech-language skills**
  - **1 audiologist with expertise in childhood hearing status determination**
  - **1 Maryland Association of the Deaf representative**
  - **1 Alexander Graham Bell Association of Maryland Representative**
  - **EFFECTIVE July 1, 2014: 1 Governor's Office of the Deaf and Hard of Hearing representative**

Hearing Advisory Council

- The council's chairperson is elected from the membership. The current chairperson is Jennifer Reesman, Ph.D. She fulfills the membership capacity of mental health professional with expertise in the area of deafness. She is a neuropsychologist at the Kennedy Krieger Institute's Deafness Related Evaluations and More (DREAM) Clinic.

- The council meets bi-monthly. Meetings are open to the public.

- The council has been extremely instrumental in ensuring the engagement of stakeholders in the EHDI process in Maryland. Members have actively participated in EHDI activities, assisted with review and recommendations for legislation revisions. Council workgroups are assembled as necessary to provide input to DHMH on hearing screening and diagnostic protocols recommendations and communications.

MD EHDI Federal Grants

- Health Resources and Services Administration (HRSA)
- Centers for Disease Control and Prevention (CDC)

HRSA

Funding Purpose: To reduce loss to follow up/loss to documentation (LTF/LTD) after failure to pass the newborn hearing screening

Current Grant Initiatives through August, 2014: To continue to reduce LTF/LTD through the daily efforts of the Program's two full-time follow-up coordinators; To continue to ensure family/parent participation in its program and policy activities (includes the *Parent Connections* Parent to Parent Mentor Program through the Parents Place of Maryland).

Proposed Grant Initiatives – September, 2014 – August, 2017:

Efforts to reduce LTF/LTD are aimed at addressing the barriers of access to services, compliance with data reporting, and coordination of care between providers and agencies. Outreach and education for families and providers, along with collaborative efforts among state agencies will be used. For this grant period, the primary target geographic locations will be Baltimore City, Baltimore County and Prince Georges County where an extensive needs assessment revealed the largest number of babies who are LTF/LTD occur.

CDC Award

Goal: The goal of this project is to enhance the state's infant hearing data system in order to address data system needs that contribute to the lost to follow-up/lost to documentation rate for babies who miss or do not pass the newborn hearing screening.

Recently completed: Established a data linkage between the MSDE Early Intervention data system to the MD EHDI data system.

Currently in progress: Connecting the MD EHDI data system to the state's HIE (Health Information Exchange) to allow for auto-population of demographic data between the 2 systems and reducing the data entry burden for staff.

In the development phase: Developing an Early Hearing Care Plan which will allow transfer of hearing health information and follow up recommendations to providers who are connected to the state's HIE (CRISP)

Near future (2015): Development of an auto-update feature for patient records which will reduce the manual data entry burden even further by importing accurate birth defect data from the hospital labor and delivery summary into the MD EHDI data system.

MARYLAND
Department of Health and Mental Hygiene

Raising Awareness of CMV as a risk factor for later onset hearing loss

MARYLAND
Department of Health and Mental Hygiene

National EHDI Conference

2014

Jacksonville, FL

2015

Louisville, KY

March 8-10

It's All Good for EHDI:

How Other Programs and MD EHDI benefit from Data Integration

Tanya Green, MS, CCC-A[1]; Erin Filippone, MEd, CCC-A[1]; Brenée Mitchell, MS[2]

1 - Maryland Department of Health and Mental Hygiene, 2 – OZ Systems

Objective

To achieve CDC's goal of reducing hospital reporting burden, Maryland (MD) Department of Health and Mental Hygiene EHDI Program added Birth Conditions reporting and Critical Congenital Heart Disease (CCHD) screening as new modules in the existing EHDI information system (IS). MD also sought to improve reporting for Early Intervention data and expand opportunities for hospitals to report demographic data from the State's Health Information Exchange (HIE).

Methods

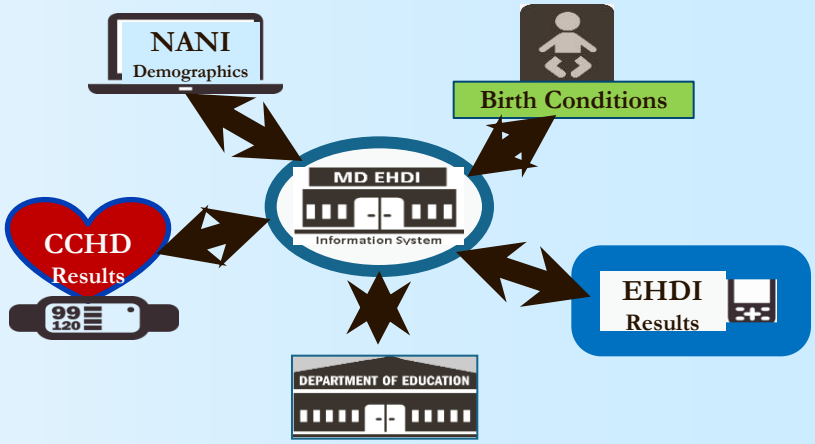
MD's EHDI IS, provided by its vendor, OZ Systems, was updated to achieve the goal of reducing hospitals' reporting burden.

1. CCHD Screening and Birth Conditions modules were integrated into the EHDI IS and introduced to all MD hospitals for daily Screening, Tracking, Analyzing and Reporting - STAR.
2. New or existing State and Hospital staff with proper credentials were provided access and trained on new modules.
3. A link was created for Early Intervention data from MD's Department of Education (MSDE) to populate the EHDI IS.
4. Newborn Admission Notification Information (NANI) was introduced to send electronic HL7 messages from the HIE to EHDI IS .

Results

Integrating multiple child health programs has created heightened awareness of all three programs by hospital management and nursery staff.

1. Birth Conditions Reporting has increased by 1/3, with the data being more complete and detailed.
2. Adding CCHD and Birth Conditions has resulted in a significant increase in reporting infant's time of birth, gestational age and birth weight for all programs.
3. Hospitals have become more attentive to tracking their compliance in reporting their data. The system allows them to easily find babies not documented as screened, resulting in better reporting and compliance each month.
4. Hospital participation in electronic demographics reporting through the State HIE is increasing.
    a. Hospitals are implementing standardized HL7 ADT messages to populate the MD database via the State HIE (CRISP).
    b. EHDI follow-up is able to begin earlier than before as patient discharges are noted in real time.
5. Incorporating Early Intervention data directly from MSDE has improved tracking referrals to EI. MD EHDI is able to verify receipt of referrals by EI programs and can re-send data for any infant who does not have a documented EI registration.
6. Multiple program analysis and reporting are available in one integrated IS.



Conclusions/Lessons Learned

A primary objective, to reduce the reporting burden, is being achieved with better data in all programs.

1. Robust matching algorithms and clear implementation guides were found to be vital in successfully transmitting data to a shared, comprehensive record. This included training screeners to accurately enter data into screening devices.
2. Monitoring the match rate is an ongoing process and requires educating staff to improve the quality and format of data entry into the standard required for matching.
3. For Birth Conditions, the goal was to increase reporting and to receive complete information; however, the method of requiring data entry in a single session was found to dissuade users from reporting until all information was obtained. This potentially impacted timely care. System updates are in progress to allow users to save and then return to update.
4. Quality improvements can be difficult to measure as a program often does not know what it does not know. Anecdotal evidence suggests that each program receives more data in less time. As new hospitals transmit from the HIE to MD's IS, the data will be even more complete, more accurate and available in real time. The inclusion of the MSDE link provides substantially more data on EI enrollment.

Maryland EHDI and its Valued Stakeholders Working Together

Families

Healthcare Providers (physicians, nurse practitioners, audiologists, early intervention providers)

Hearing Advisory Council

Community, Non-Profit, and Professional Organizations that contribute to the EHDI system

State Agencies

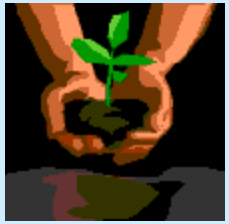
Parent Connections - Parent Mentor Program, through the Parents Place of Maryland

Maryland State Department of Education

Maryland School for the Deaf

CRISP – Chesapeake Regional Information System for our Patients (Maryland's Designated HIE/Health Information Exchange)

Let's Continue to Grow Together



Helpful Information:

Link to Passed Bill: http://mgaleg.maryland.gov/2014RS/bills/sb/sb0103e.pdf

EHDI-PALS online database: www.ehdipals.org
Pediatric Audiology Links to Services – web-based link to information, resources and services for children with hearing loss including an audiology facility locator.

Link to OGPSHCN Resource Locator Database:
http://specialneeds.dhmh.maryland.gov

Link to MD EHDI:
http://phpa.dhmh.maryland.gov/genetics/SitePages/Infant_Hearing_Program.aspx

The MD EHDI Advisory Council meets bi-monthly on the 3rd Thursday, beginning in January. Meetings are open to the public and are held at 12:30 pm at the Hearing and Speech Agency in Baltimore. ***The next meeting will be held on July 17th, 2014.***

Maryland Infant Hearing Program

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Thanks for all you do for Maryland's babies and families!!

This presentation will be made available on the MD EHDI website.

http://phpa.dhmh.maryland.gov/genetics/SitePages/Infant_Hearing_Program.aspx